



## ***New Jersey Commission on Spinal Cord Research Spinal Cord Injury Registry***

The New Jersey Commission on Spinal Cord Research was created in 1999 by the “Spinal Cord Research Act” to encourage and promote significant, original research projects in New Jersey through the funding of approved research projects at qualifying research institutions in the State. In addition, the Commission is charged with the responsibility for establishing and maintaining, in conjunction with the New Jersey Department of Health and Senior Services, a central registry of all persons who sustain spinal cord injuries. (N.J.S.A. 52:93E-8(a))

### ***THE NEW JERSEY SPINAL CORD INJURY REGISTRY***

One component of the Spinal Cord Research Act requires hospitals to submit additional data on individuals hospitalized in New Jersey with spinal cord injuries. This information is reported to The Center for Health Statistics of the New Jersey Department of Health and Senior Services.

The purpose of the New Jersey Spinal Cord Injury Registry is to:

- Provide information to injured individuals concerning research on spinal cord injuries.
- Create a database of injured individuals who are potentially interested in participation in clinical research trials.
- Provide researchers with data that may be useful in conducting spinal cord research.
- Provide more detailed information about the incidence of spinal cord injuries, in order to aid prevention efforts.

### ***HOW DO I BECOME PART OF THE REGISTRY?***

If you meet the following criteria, you may use the attached form to enroll in the registry:

- You are presently living in New Jersey, and
- You sustained a spinal cord injury requiring hospitalization.

### ***CAN I ENROLL SOMEONE OTHER THAN MYSELF IN THE REGISTRY?***

You can provide information about a person other than yourself to the New Jersey Spinal Cord Injury Registry as long as that person meets the criteria above and gives written permission as evidenced by his/her signature or the signature of the guardian or designated person on this reporting form.

The form is available electronically at: [www.state.nj.us/health/spinalcord/](http://www.state.nj.us/health/spinalcord/)

Simply complete the information requested on this form and mail to:

**New Jersey Commission on Spinal Cord Research  
Registry Manager  
PO Box 360  
Trenton, New Jersey 08625-0360  
Phone: 609-292-8711  
Fax: 609-943-4213  
Email: [NJCSCR@doh.state.nj.us](mailto:NJCSCR@doh.state.nj.us)**

***WILL INFORMATION PROVIDED TO THE REGISTRY REMAIN CONFIDENTIAL?***

**YES!** Confidential information is any information that can potentially be used to identify an individual. This includes names and addresses, but also information such as date of birth and zip code of residence. Confidential information from the Spinal Cord Injury Registry is maintained by the New Jersey Department of Health and Senior Services and is not shared with anyone except legitimate researchers who have made successful applications to the Institutional Review Board in which they provide multiple assurances that they will not violate anyone's confidentiality.

However, you will not be contacted by any researcher unless you have affirmatively answered Question #25 on the Registry Enrollment Application form and signed in the "CONSENT TO BE CONTACTED" portion of the form.

You may be removed from the registry at any time or revoke your consent to be contacted simply by contacting the registry manager at the address stated above.

New Jersey Commission on Spinal Cord Research  
PO Box 360  
Trenton, New Jersey 08625-0360

**SPINAL CORD INJURY REGISTRY  
APPLICATION FOR ENROLLMENT**

Name <i>(First, Middle, Last)</i>		Date of Birth <i>(Month/Day/Year)</i>	
<input type="text"/>		<input type="text"/>	
Street Address			
<input type="text"/>			
City	State	Zip Code	
<input type="text"/>	<input type="text"/>	<input type="text"/>	
Telephone Number <i>(Include Area Code)</i>		Email Address <i>(Optional)</i>	
<input type="text"/>		<input type="text"/>	
Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female			
Race: <input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Hispanic <input type="checkbox"/> Other (specify): <input type="text"/>			

**INJURY INFORMATION**

1. Date of Injury <i>(Month/Day/Year)</i> :	2. Age at Time of Injury:
<input type="text"/>	<input type="text"/>
3. Type of Injury: <input type="checkbox"/> Spinal Cord Injury <input type="checkbox"/> Brain Injury <input type="checkbox"/> Both	
4. What caused your injury <i>(PLEASE CHECK ONLY ONE ITEM)</i> :	
<input type="checkbox"/> Transportation -- <b>GO TO QUESTION #5</b>	
<input type="checkbox"/> Unintentional Fall -- <b>GO TO QUESTION #6</b>	
<input type="checkbox"/> Sports/Recreation -- <b>GO TO QUESTION #7</b>	
<input type="checkbox"/> Assault/Self-Inflicted -- <b>GO TO QUESTION #8</b>	
<input type="checkbox"/> Non-trauma -- <b>GO TO QUESTION #10</b>	
5. When your transportation injury occurred, what was your position? <i>(PLEASE CHECK ONLY ONE ITEM)</i>	
<input type="checkbox"/> Motor Vehicle Driver	
<input type="checkbox"/> Motor Vehicle Passenger	
<input type="checkbox"/> Motorcyclist	
<input type="checkbox"/> Pedestrian	
<input type="checkbox"/> Bicyclist	
<input type="checkbox"/> Other (Please explain): <input type="text"/>	
<b>GO TO QUESTION # 9</b>	
6. How did you fall? <i>(PLEASE CHECK ONLY ONE ITEM)</i>	
<input type="checkbox"/> From a ladder or building	
<input type="checkbox"/> From stairs	
<input type="checkbox"/> From a chair or a bed	
<input type="checkbox"/> Other (Please explain): <input type="text"/>	
<b>GO TO QUESTION # 9</b>	

## APPLICATION FOR ENROLLMENT (Continued)

7. What activity were you doing when you sustained your injury? *(PLEASE CHECK ONLY ONE ITEM)*

- ☐ Team Sports (football, baseball, soccer, etc.)
- ☐ Water Sports (swimming, diving, water ski, etc.)
- ☐ Combative Exercise (martial arts, boxing, etc.)
- ☐ Cheerleading or Gymnastics
- ☐ Horseback Riding
- ☐ Fishing/Hunting
- ☐ Ice Skating, Roller Skating, Skateboard, Scooter
- ☐ Snow Sports (skiing, snowboarding, toboggan)

☐ Other (Please explain):

**GO TO QUESTION # 9**

8. What weapon caused your injury?

☐ Firearm

☐ Other (Please explain):

**GO TO QUESTION #11**

9. Was your injury work related?

☐ Yes

☐ No

**GO TO QUESTION #11**

10. IF NOT TRAUMA RELATED, what caused your injury? *(PLEASE CHECK ONLY ONE ITEM)*

☐ Tumor

☐ Ischemic

☐ Other (Please explain):

**GO TO QUESTION #11**

11. What was the level of your spinal cord injury, AT THE TIME OF YOUR INJURY? *(PLEASE CHECK ONLY ONE ITEM)*

☐ C1 - C8 (Cervical)

☐ L1 - L5 (Lumbar)

☐ T1 - T12 (Thoracic)

☐ S1 - S5 (Sacral)

12. What is the level of your spinal cord injury, NOW? *(PLEASE CHECK ONLY ONE ITEM)*

☐ C1 - C8 (Cervical)

☐ L1 - L5 (Lumbar)

☐ T1 - T12 (Thoracic)

☐ S1 - S5 (Sacral)

13. What was your ASIA score, AT THE TIME OF YOUR INJURY? *(PLEASE CHECK ONLY ONE ITEM)*

☐ A

☐ B

☐ C

☐ D

☐ E

☐ NOT SURE

14. What is your ASIA score, NOW? *(PLEASE CHECK ONLY ONE ITEM)*

☐ A

☐ B

☐ C

☐ D

☐ E

☐ NOT SURE

15. Check the level of spinal cord injury that best describes your situation now:

☐ Require a ventilator to assist with breathing

☐ Paralyzed from the shoulders down

☐ Have **limited** use of arms/hands, use wheelchair

☐ Have **full** use of hands, use wheelchair

☐ Have full use of hands, **walk with assistance**

☐ Have full use of hands, **limited ability to walk**

☐ No impairments at this time

☐ Other (PLEASE DESCRIBE):

## APPLICATION FOR ENROLLMENT (Continued)

16. At the time of your injury, were you: *(PLEASE CHECK ONLY ONE ITEM)*:

- ☐ Seen at the emergency room only -- **GO TO QUESTION #20**
- ☐ Discharged from the emergency room -- **GO TO QUESTION #20**
- ☐ Seen in a doctor's office/clinic only -- **GO TO QUESTION #20**
- ☐ Admitted to the hospital
- ☐ Transferred to another hospital

17. IF ADMITTED TO THE HOSPITAL, where did you go after you were discharged? *(PLEASE CHECK ONLY ONE ITEM)*

- ☐ Rehabilitation Facility
- ☐ Home -- **GO TO QUESTION #21**
- ☐ Nursing Home -- **GO TO QUESTION #21**
- ☐ NOT SURE -- **GO TO QUESTION #21**

☐ Other (Please explain):

**GO TO QUESTION #21**

18. What is the name of the rehabilitation facility where you were treated?

19. How long did you stay at the rehabilitation facility?

20. Please list the name(s) of the hospital(s) or clinic(s) where you were treated at the time of your injury:

1.

2.

3.

4.

21. From the time of your injury, how long was it until you underwent surgery?

- |                                     |                                      |  |
|-------------------------------------|--------------------------------------|--|
| <input type="checkbox"/> Never      | <input type="checkbox"/> 1 - 2 Weeks | <input type="checkbox"/> 2 - 6 Months  |
| <input type="checkbox"/> 24 Hours   | <input type="checkbox"/> 3 - 4 Weeks | <input type="checkbox"/> 7 - 12 Months |
| <input type="checkbox"/> 48 Hours   |                                      |  |
| <input type="checkbox"/> 3 - 4 Days |                                      |  |
| <input type="checkbox"/> 5 - 6 Days |                                      |  |

22. Did you receive Methylprednisolone (steroid) at the time of the injury?

- ☐ Yes    ☐ No    ☐ NOT SURE

23. At the time of your injury, what insurance coverage did you have?

- ☐ Automobile Insurance
- ☐ Commercial Insurance (HMO, PPO, POS)
- ☐ Medicare
- ☐ Medicaid
- ☐ No insurance

☐ Other (PLEASE DESCRIBE):

24. Would you be interested in receiving additional information regarding possible clinical trials?

- ☐ Yes    ☐ No

25. Would you like to be contacted for possible participation in clinical trials?

- ☐ Yes    ☐ No

## APPLICATION FOR ENROLLMENT (Continued)

Below we request your signature for consent to allow researchers 1) to use the information you provided on the registry form for research purposes, and 2) to contact you for possible participation in clinical trials. Please note that all the information you provide will be kept CONFIDENTIAL and used solely by researchers who have agreed to the stated terms of confidentiality. Also note that even if you answered Yes to question #25 above, you must also sign below in the CONSENT TO BE CONTACTED section of the form.

### **1. CONSENT TO USE INFORMATION FOR RESEARCH PURPOSES**

I hereby authorize the New Jersey Commission on Spinal Cord Research permission to use the information contained herein for informational purposes and research purposes.

Completed By:

Date:

\_\_\_\_\_  
*Name (Print)*

\_\_\_\_\_  
*Month/Day/Year*

\_\_\_\_\_  
*Signature of Person with Spinal Cord Injury*

**OR**

\_\_\_\_\_  
*Signature of Parent/Guardian/Designated Person*

### **2. CONSENT TO BE CONTACTED**

I hereby authorize the New Jersey Commission on Spinal Cord Research to provide my contact information to researchers who are looking for persons to participate in clinical trials.

Completed By:

Date:

\_\_\_\_\_  
*Name (Print)*

\_\_\_\_\_  
*Month/Day/Year*

\_\_\_\_\_  
*Signature of Person with Spinal Cord Injury*

**OR**

\_\_\_\_\_  
*Signature of Parent/Guardian/Designated Person*

Complete the information requested on this form and return to:

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